

PATIENT CONSENT PREFERENCES & DATA SECURITY WORK GROUP PROJECT CHARTER

KEY TERMS

Patient consent preferences: Patient consent preferences can be expressed by a patient identifying the PHI the patient is comfortable sharing via the ILHIE in specific circumstances. The policies and technical infrastructure that support patient consent preferences must be consistent with state and federal laws and reasonable in relation to the capabilities of the ILHIE and its participating providers.

Data security: Data security ensures the protection of PHI in electronic format, including ensuring appropriate and authorized access to PHI in an electronic format and the protection of electronic PHI received, created, maintained, in transit and in rest.

Key roles relative to patient consent preferences to transmit PHI via ILHIE:

Patient	Provider	ILHIE
Exercise choice	Register and transmit choice Determine purpose of PHI	Register and transmit choice Transmits PHI

WORK GROUP DIRECTIVE

The Work Group will proceed by first defining the current capabilities of the ILHIE and how these capabilities interact with connected health care service provider sites. We expect to demonstrate one or two potential approaches to protecting patient data privacy based on prototypes that have been developed recently in Illinois by the ILHIE in collaboration with the Strategic Health IT Advance Research Project (SHARP) and at the Substance Abuse and Mental Health Services Administration (SAMHSA). The work group also will establish the current state of segmenting records.

The Work Group will move on to enumerating specific data security concerns that come from specific patient consent preference scenarios. These concerns and scenarios will be mapped to elements of electronic exchange which will allow the Work Group to make concrete recommendations to the Authority on protecting patient data.

DELIVERABLES

- Documentation of the current capabilities of the ILHIE and how these capabilities interact with connected medical practices and other entities
- A summary of the current state of segmenting records
- A list of patient privacy concerns with a representative sample of associated scenarios
- A list of how the above concerns impact or are impacted by electronic exchange through the ILHIE
- Recommendations for how the ILHIE can address the items in 3 above. The recommendations will be prioritized according to the scenario and the population impact. The recommendations will be evaluated according to the benefits and disadvantages of each scenario and the feasibility for technical implementation. Feasibility must address resource requirements, length of time for implementation and scalability.

MAJOR ACTIVITIES

1. Establish the current capabilities of the ILHIE and EMR systems to manage data segmentation and at what level of granularity
2. Explain or educate on EMR products and their capability as it relates to consent.
3. How does Meaningful Use impact: medical records, privacy
4. Review SAMHSA demo and assessment of SAMHSA strategic direction regarding record/data segmentation
5. Review SHARP's prototype
6. Identify specific patient consent preference scenarios
7. Map elements of identified scenarios to elements of electronic exchange
8. Develop recommendations to the ILHIE Authority Board regarding statutory requirement for annual review of the technology to support record segmentation; prioritize according to population impact and technical feasibility

TIMELINE

- **Monthly meetings**
- **Sept/Nov 2013** – Progress updates at Authority Board meetings
- **Q1 2014** – Preliminary recommendations to the Authority Board
- **Q2 2014** – Final approval by Authority Board (Work Group deliverables)
- **June 2014** – Proposed annual technology review of feasible technical capabilities to support patient consent preferences

WORKSHOP HANDOUTS

- Summary of the C-CDA (Consolidated-CDA)
 - Describe continuity of care records discussion of CDA, C32, CCDA
 - Different section headings that fall under C32 and CDA
 - Describe basic constraints
- Brief description with links to the following:
 - Presentation/video on HealthShare
 - SAMHSA demo
 - SHARP's prototype
 - Vocabularies
- Proposed mechanism based on current laws

STAKEHOLDER ROLE

- Identify stakeholder concerns regarding patient consent preferences
 - How are these concerns impacted by electronic exchange through an HIE?